Transgender Health
Volume 8, Number 2, 2023
© Mary Ann Liebert, Inc.
DOI: 10.1089/trgh.2021.0030

Open camera or QR reader and scan code to access this article and other resources online.

REVIEW

Supporting Gender-Related Medical Decision Making for Transgender and Gender-Diverse Individuals: A Scoping Review

Amy Lambert,[1] Ashli Pratt,[1] Lee Ann E. Conard,[1,2] Elaine Grigg Dean,[1] Erica Page,[1] Lisa M. Vaughn,[1,2] and Ellen A. Lipstein[1,2,*]

Abstract

Purpose: Transgender and gender-diverse (TGD) individuals and their families face numerous challenging decisions. To better understand their decision processes, we conducted a scoping review of the existing literature and of decision-support tools in use at pediatric gender-care clinics.

Methods: We searched PubMed, EMBASE, Scopus CINAHL, PsychINFO, and EBM Reviews for studies that were original research focused on decisions, decision making, or decision support for TGD individuals and/or their families. All studies were reviewed for inclusion by at least two researchers. Additionally, we reviewed clinical tools used to support decision making by TGD youth and their families.

Results: We retrieved 3306 articles. Thirty-two met criteria for data extraction. Studies focused on three major decisions: gender-confirming surgery, fertility preservation, and gender-affirming hormone therapy. Several themes that cut across clinical topics emerged: decision-making processes, decision-making roles, and sources of decision support. Only three articles focused on decision-support interventions, two of which discussed development of support tools and one evaluated a class designed to help with surgical decision making. None of the clinical tools reviewed met criteria for a decision aid.

Conclusions: There is a dearth of studies related to decision support interventions, an absence validated by the resources currently in clinical use. This scoping review suggests an opportunity for the development of tools to aid in the decision-making processes for TGD youth and their families.

Keywords: decision aid; decision making; decision support interventions; gender-related health care; transgender youth

Introduction

Transgender and gender-diverse (TGD) individuals face numerous decisions complicated by social and medical uncertainty. This decision-making complexity can be challenging and impact when an individual's gender dysphoria is fully addressed. For all TGD individuals, but perhaps especially adolescents, the interactions between health care providers, themselves, and their family are crucial aspects of the decision-making process. Given the multiple approaches to addressing gender dysphoria,[1] the lack of long-term treatment data[2,3] and the crucial role of patient preferences in such decisions'[4,5] shared decision making, in which the patient and clinician work together to make a decision consistent with medical evidence and the patient's goals, may be the ideal approach.

However, prior research shows that the process of gender-care decision making for adolescents, specifically related to starting gender-affirming hormone therapy, is unlike other medical decisions.[6] In fact, the decision may hinge more on personal and family acceptance of the youth's gender identity than medical

[1]Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA.
[2]Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, Ohio, USA.

*Address correspondence to: Ellen A. Lipstein, MD, MPH, Department of Pediatrics, University of Cincinnati College of Medicine, 3333 Burnet Avenue, Cincinnati, OH 45208, USA, E-mail: ellen.lipstein@cchmc.org

risks. As such, models of shared decision making focused exclusively on medical decision making,[7] are likely to be insufficient for supporting TGD adolescents' decision making. A new multidimensional model of shared decision making that explicitly incorporates both social and medical aspects of decision making will be required to best support TGD adolescents and their families as they make gender-related decisions.

A key step to generating such a model is a deep understanding of the current approach to gender-care decision making. To begin developing such an understanding, we conducted a scoping review of both the existing literature on gender-related health care decision making and the decision support tools currently used in clinical practice. As research focused on the care of TGD youth has only recently become a focus in the medical literature, this scoping review includes both adult and youth-focused studies.

Methods

Literature review

Data sources and searches. Following the PRISMA guidelines for scoping reviews,[8] (Supplementary Appendix SA1) we searched PubMed (MEDLINE), Elsevier EMBASE, Scopus, CINAHL (EBSCO), PsycINFO (EBSCO), and the EBM Reviews (OVID) from their earliest dates through July 7, 2021. A medical librarian (E.G.D.) developed database-specific search strategies.[9] Studies retrieved included the selected gender terms, decision terms, and patient/family preference terms. (Table 1) Results were limited to English language and excluded animal studies. A reproducible PubMed search strategy is provided in Supplementary Appendix SA2.

After reviewing the articles from this search strategy, we examined the reference lists of all included articles to identify articles that the search strategy missed.

Eligibility criteria. We included studies focused on TGD individuals (youth or adults) or their family members and gender care-related health care decisions or decision processes. If TGD individuals or their families were a subset of study participants, but the data were presented only as a part of a heterogeneous group of participants (e.g., sexual and gender minorities), the study was excluded. All original research was included. We excluded editorials, opinion pieces, expert statements, reviews, letters to the editor, conference abstracts, and studies not published in English.

Selection process. Three rounds of review were conducted: title, abstract, and full article (Fig. 1). In each round, each study was independently assessed by at least investigators. Rayyan QCRI was used to facilitate review and comparison. Following the independent reviews, the research team met to discuss any conflicts. In situations where the team did not quickly reach a consensus, we took a conservative approach and included the study in the next level of review.

Data extraction and analysis. The full review of each included article was done independently by two team members using a template, which included fields for study aims, context, population, design, area of decision focus, and findings. Reviewers met during the extraction process to resolve differences. Once extraction was complete, the team reviewed the data, and organized findings into themes.

Tool review

Data sources. We emailed all pediatric transgender clinics listed on the Human Rights Campaign website,[10] asking them for, "any tools or resources (handouts, websites, etc.) you use to help adolescents and parents make gender care-related decisions." Nonresponders were sent a second email, followed

Table 1. Keywords from Literature Search Strategy

Gender terms	"cross gender", "gender change", "gender confirming", "gender dysphoria", "gender expansive", "gender fluid", "gender identity", "gender minorities", "gender minority", "gender non-conforming", "gender queer", "gender reassignment", "gender transition", "gender variant", "gender affirming", "non-binary", "sex reassignment", "third gender", "trans female", "trans individual", "trans male", "trans man", "trans men", "trans people", "trans person", "trans woman", "trans women", "two spirit", transsexualism, agender, androgynous, bigender, crossgender, genderfluid, genderfuck, genderless, genderqueer, non-binary, non-gendered, nonbinary, transexual, transgender, transman, transmen, transpeople, transperson, transsexual, transwoman, transwomen, two-spirit
Decision terms	decision aid*, decision tool*, decision box*, option grid*, issue card*, "drug fact" box*, shared decision*, informed decision*, informed choice*, collaborative decision*, decision support intervention*, decision making, decision support, decision making, decision support
Patient engagement terms	patient participat*, patient engagement, patient involvement, participat*, engagement, involvement, patient relation*, patient preference*, patient centered, patient centred

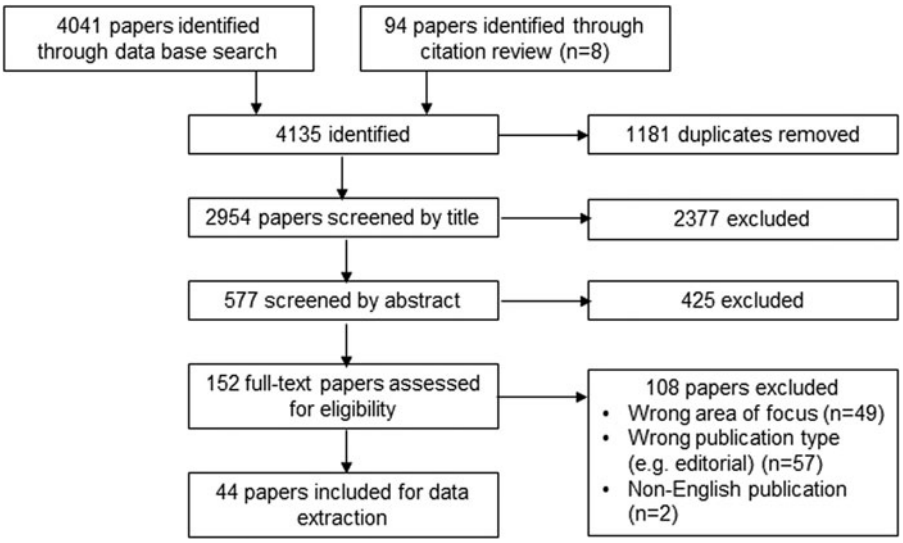
4041 papers identified through data base search
94 papers identified through citation review (n=8)
4135 identified
1181 duplicates removed
2954 papers screened by title
2377 excluded
577 screened by abstract
425 excluded
152 full-text papers assessed for eligibility
108 papers excluded
• Wrong area of focus (n=49)
• Wrong publication type (e.g. editorial) (n=57)
• Non-English publication (n=2)
44 papers included for data extraction

FIG. 1. Flow chart of search results and screening for inclusion.

by a phone call. We also sent a request for decision support tools to a pediatric transgender health care provider, listserv.

Eligibility criteria. We planned to include only tools that met the International Patient Decision Aid Standards (IPDAS)-qualifying criteria.[11] However, preliminary review of material received indicated that would be overly stringent given that virtually none of the tools explicitly stated the decision that needed to be considered nor described more than one option. Therefore, we changed our plan and evaluated all items.

Evaluation. Items were categorized by format, decision focus, and target audience. We further classified resources by the type of information contained. Those with information about more than one option were subdivided into three categories based on whether they only listed the options, listed the options and risks and benefits of each, or listed multiple options and risks and benefits in a format that facilitated easy comparison.

This study was considered non-human subjects research by the local IRB.

Results

Sample

We identified 4135 articles. After removing 1181 duplicates we screened a total of 2954 articles (Fig. 1). In the end, 44 articles were included for data extraction. Of these, 18 were qualitative studies, 16 presented survey results, and six used mixed methods. Additionally, there were two chart reviews, one case study, and one intervention evaluation (Table 2). Fifteen focused on youth, 25 on adults, and four did not specify. Thirty-four (77%) of the articles studied either gender-affirming hormone therapy ($n=7$), fertility preservation ($n=13$), or gender-affirming surgery ($n=14$). Four articles discussed decision-support interventions, of which two discussed development of support tools,[12,13] one evaluated a decision aid,[14] and one assessed a class designed to help with decision making.[15]

Of the 57 clinics to whom we sent a request for decision-making tools, 15 responded. One institution responded to our listserv request. We received a total of 150 resources, of which five were duplicates.

Synthesis of published literature

The literature synthesis is organized by the major decision foci of the articles, followed by decision process themes present across decisions. No articles focused on the role of insurance, health, or legal systems in decision making. Throughout the results and tables, when discussing a specific article, we use the gender terminology of the cited article.

Gender-confirming surgery. The gender-confirming surgical decision process, which is long and complex,[16] may be hindered by a lack of data.[17] Influences

Table 2. Characteristics of Included Studies

First author, publication year	Country	Number of participants	Age of participants (years)	Gender of participants[a]	Study design	Decision focus
Agenor, 2020[52]	United States	21	18–29	Male ($n=5$), Transgender men ($n=9$), Trans masculine ($n=5$), Nonbinary ($n=23$)[d]	Qualitative interviews	Hormonal contraception
Aguayo-Romero, 2015[25]	Colombia	83	18–47	transgender persons/assigned male at birth ($n=83$)	Qualitative interviews and a focus group	Surgery
Atnas, 2015[16]	United Kingdom	11	19–69	Trans men ($n=11$)	Qualitative interviews	Surgery
Bartholomaeus, 2019[40]	Australia	295	18+ (median age, 25)	Female ($n=72$), Male ($n=100$), Nonbinary ($n=102$), Agender ($n=21$)	Survey (focus on qualitative analysis of open-ended questions)	Fertility preservation
Beek, 2015[45]	Netherlands	360	18–77	Natal Men ($n=233$), Natal Female ($n=127$)	Quantitative analysis of treatment requests	General
Benson, 2020[23]	United States	50	18–34	Trans masculine ($n=50$)	Retrospective chart review	Surgery
Bernacki, 2019[18]	United States	1	15	Trans masculine/Trans man; assigned female at birth ($n=1$)	Case study	Surgery
Birenbaum-Carmeli, 2020[33]	United States and Israel	4	20–30	Transgender men ($n=4$)	Ethnographic interviews	Fertility preservation
Chen, 2018[39]	United States	156	14–17	Transgender and gender nonconforming: Birth assigned sex: male ($n=26$), female ($n=130$)	Survey	Fertility preservation
Chen, 2019[34]	United States	18	15–24	Assigned female at birth ($n=12$), assigned male at birth ($n=6$)	Qualitative interviews	Fertility preservation
Clark, 2019[48]	Canada	5 transgender patients and 10 providers	16–18 (patients)	Transgender youth, gender not specified	Qualitative interviews	Gender-affirming hormones
Clark, 2020[42]	Canada	21 transgender youth and 15 parents	14–18 (adolescents)	Transgender females ($n=8$), Transgender males ($n=8$), Nonbinary ($n=5$), Parents ($n=15$)	Qualitative interviews and lifeline drawings	Gender-affirming hormones
Clark, 2020[49]	Canada	21 transgender youth, 15 parents, and 11 health care providers	14–18 (adolescents)	Transgender ($n=21$), Parents ($n=15$), and Health care providers ($n=11$)	Qualitative interviews	Gender-affirming hormones
Clark, 2021[43]	Canada	21 transgender youth, 15 parents, and 11 health care providers	14–18 (adolescents)	Transgender ($n=21$), Parents ($n=15$), and Health care providers ($n=11$)	Qualitative interviews	Gender-affirming hormones
Daley, 2019[6]	United States	17 adolescents and 13 parents	14–19 (adolescents)	Self-described as: Male ($n=16$) or Masculine aligned ($n=1$); parents identified as mother ($n=10$) and father ($n=3$)	Qualitative interviews	Gender-affirming hormones
de Blok, 2020[19]	Netherlands	773	35–59	Trans women ($n=773$)	Survey	Surgery
Ettner, 2016[22]	United States	101	14–80	Trans women ($n=54$) and cisgender patients ($n=47$)	Survey	Surgery
Evans, 2017[53]	United States	50 caregivers of transgender youth; 15 self-identified transgender youth	youth: 14–22 and caregivers: 29–71 of transgender youth 22 years of age or younger	Youth: Trans feminine ($n=3$), Trans masculine ($n=7$), Other ($n=5$); Caregivers: female ($n=40$) and male ($n=7$)	Mixed Methods (focus groups, interviews and survey)	General
Eyssel, 2017[46]	Germany	415	16–76 (average 38)	Assigned female at birth ($n=216$) and assigned male at birth ($n=199$)	Survey	General
Fein, 2017[44]	United States	148	18+	Female to male ($n=68$) and male to female ($n=80$)	Survey	General

(*continued*)

Table 2. (Continued)

First author, publication year	Country	Number of participants	Age of participants (years)	Gender of participants[a]	Study design	Decision focus
Garcia, 2017[28]	United Kingdom	25	average 36.1	Female to Male ($n=25$)	Qualitative interviews	Surgery
Hoffkling, 2017[17]	United States	10	18+	Transgender Men ($n=10$)	Qualitative interviews	Fertility preservation
Jacobsson, 2017[20]	Sweden	47	18–52	Trans men /female-to-male ($n=47$)	Survey	Surgery
Jiang, 2018[21]	United States	486	17–74	Trans feminine/female/nonbinary[b]	Mixed Methods (medical record review and interviews)	Surgery
Johnson, 2016[12]	United States	12	Not specified	Health care providers (gender not specified)	Survey	Fertility-related care
Jokic-Begic, 2014[26]	Croatia	6	24–42	Female to male ($n=3$) and male to female ($n=3$)	Survey	Surgery
Kerman, 2021[35]	United States	23	13–19	Trans feminine ($n=10$), Trans masculine ($n=9$), Nonbinary ($n=4$)	Mixed methods (Qualitative interviews and surveys)	Fertility preservation
Kyweluk, 2018[29]	United States	18	15–24	Assigned Female at Birth ($n=12$) & Assigned Male at Birth ($n=6$); of which affirmed gender was trans man ($n=7$), man ($n=7$), nonbinary ($n=1$), trans woman ($n=5$), woman ($n=1$)[c]	Qualitative interviews	Fertility preservation
Linander, 2017[50]	Sweden	14	23–69	Female ($n=7$), Male ($n=4$), nonbinary or Intergender ($n=3$)	Qualitative interviews	General
Mayer, 2019[51]	Germany	415	16–76	Trans/non-cisgender: Assigned Female at Birth ($n=216$) and Assigned Male at Birth ($n=199$); of which gender identity was binary ($n=339$) or nonbinary genderqueer ($n=76$)	Survey	General
Mokken, 2020[14]	Netherlands	51	19–51	Trans men ($n=51$)	Mixed Methods (Qualitative interviews and questionnaires)	Gender-affirming hormones
Nahata, 2017[30]	United States	73	9–18	Transgender males ($n=50$) and transgender females ($n=23$)	Chart Review	Fertility preservation
Özer, 2018[13]	Netherlands	21	Not specified	Trans men ($n=12$) and health care professionals ($n=9$)	Focus groups	Surgery
Persky, 2020[36]	United States	64 transgender and queer youth and 46 parents	12–24	Youth: Trans male or male ($n=37$), Trans female or female ($n=23$), Genderqueer ($n=4$), Parents: Male ($n=11$), Female ($n=32$), Genderqueer ($n=1$)	Survey	Fertility preservation
Poceta, 2019[15]	United States	214	Not specified	Transgender and Nonbinary ($n=214$)	Postintervention survey	Surgery
Pullen Sansfaçon, 2019[41]	Canada	35 dyads (trans and gender diverse youth and their parents)	9–17; parents not reported	Trans feminine ($n=14$); Trans masculine (TM) ($n=22$); parents not specified	Qualitative interviews	General
Rachlin, 1999[24]	United States	27	21–50	"Female-bodied individuals…had male gender identity": male transexual ($n=19$), transgendered ($n=8$)	Survey	Surgery

(*continued*)

Table 2. (Continued)

First author, publication year	Country	Number of participants	Age of participants (years)	Gender of participants[a]	Study design	Decision focus
Riggs, 2018[32]	Australia	409	18–72	Female ($n=97$), Male ($n=131$), Nonbinary ($n=149$), Agender ($n=32$)	Survey	Fertility preservation
Riley, 2011[54]	Australia, United Kingdom, United States, Canada	62 (31 parent/child dyads)	0–25 (youth); 26–66 + (parents)	Youth: "Born Female, Male Gender" ($n=13$), "Born Male, Female gender" ($n=16$), Other ($n=2$); Parents: Mothers ($n=27$), Fathers ($n=3$), or Guardian ($n=1$)	Survey	General
Strang, 2018[31]	United States	25 for Development process (gender specialists, transgender youth/their parents, autistic, transgender youth/their parents); 51 for Pilot (transgender youth and their parents)	Youth development process: 13–19 Youth Pilot: 13–19 Parents not specified	Pilot: Male/transgender male ($n=14$), Female/transgender female ($n=10$), nonbinary ($n=1$)	Mixed methods (participatory measure development and pilot testing through survey)	Fertility preservation
Stuyver, 2021[37]	Belgium	12	22–47	Transgender men ($n=6$) and cisgender female partners ($n=6$)	Qualitative interviews	Fertility preservation
van de Grift, 2017[27]	Netherlands	21	Average 40.1	Trans men ($n=21$)	Mixed methods (longitudinal survey and medical record review)	Surgery
Vrouenraets, 2015[47]	Netherlands	17 health care teams (36 professionals)	Not specified	Not specified	Qualitative interviews and open-ended questionnaires	Puberty suppression
Vyas, 2021[38]	United States	70	18–50	Males ($n=13$), Females ($n=9$), Nonbinary ($n=9$), Trans female ($n=24$), Trans male ($n=8$), Gender fluid ($n=2$), Genderqueer ($n=1$), Unknown ($n=4$)	Electronic survey	Fertility preservation

[a]Using language of the cited study.
[b]Demographics provided only for those selecting vulvoplasty: Female ($n=29$), nonbinary ($n=1$).
[c]Total number for sex assigned at birth and affirmed gender are not equal as some reported more than one affirmed gender (e.g., man; trans man).
[d]Participants could select multiple under this category (i.e., gender fluid, gender queer, etc.).

on the decision process include patients' cognitive development,[18] finances,[19] and physical changes they experienced from gender-affirming hormone therapy.[19] Although, individual needs, goals, and desired results related to surgery vary.[20,21]

Factors considered when deciding about a surgeon include both skill and practical factors such as location.[22] Preferences for specific surgical technique may be influenced by the expected esthetic outcome,[14] as well as impact on areas of the body that are sites for tissue donation.[23] While health care providers, including surgeons, discuss options and related risks and outcomes with individuals seeking surgical care, they often have less influence than peers,[24] who are seen as mentors and sources of surgical information.[25]

Despite the decision-making challenges, studies report high satisfaction[21,26,27] and no regret among those who pursued surgery.[28] The one evaluation of a (Dutch) decision aid found that participants thought it would have been more helpful earlier in decision process, rather than when getting off a surgery intake wait list.[14] Integrating experiences of trans men and the challenges they have encountered, into such decision aids enhances the shared decision-making process[13] and is desired by users.[14] Another approach to supporting the decision process was a preoperative course, which led to participants feeling better informed and more prepared for surgery.[15]

Fertility preservation. A primary challenge of fertility preservation decisions is the need for individuals, who are often youth rather than adults, to imagine the likelihood of their future selves wanting children,[29–32] a preference that may change with age.[31] Gender transition may require youth to make fertility decisions earlier than their cisgender peers.[33]

Overall the decision-making process is highly individualized,[29] and influenced by families' values, opinions,[34] and support,[33] and the TGD individual's identity and preferences.[29] Some youth acknowledge being influenced by pressure from their family or a concern about disappointing them.[31] The impact of gender dysphoria and the need to stop or delay hormone treatment leads many youth and adults to choose not to pursue fertility preservation.[33,35–38] Ultimately, there is little decisional regret among those who do and those who do not choose fertility preservation.[38]

More concrete challenges to decision making include the cost of fertility preservation[33,34,38] and lack of insurance coverage for it,[38] as well as limited data.[17] Surveyed experts prioritized development of a patient decision aid focused on fertility preservation over a provider assessment tool.[12] Other studies focused on the need for information that is tailored to youth[39] and the different preferences parents and youth may have.[31] Although there were concerns about the inconsistency and limited use of fertility preservation consultations,[32,39] others found that proposals to mandate consultation may limit the decision-making agency of individuals.[40]

Gender-affirming hormones. In most cases, the decision to pursue gender-affirming hormones or puberty blockers is made by youth and parents together,[6,41] and generally takes longer for youth with less supportive families.[6] For both parents and youth, decisions about hormones occur in three phases: discovery, interaction, and reflection with all areas being impacted by the youth/parent relationship.[42] However, parents' decision making is more likely to be influenced by fear of regret, particularly related to the impact of hormones on fertility.[43] As in other decisions, variation in preferences related to treatment are common.[44,45]

Decision-making roles. TGD youth reported wanting to be more involved[6] or in charge of decision making.[46] In fact, youth may be ready to be meaningful decision-making participants based on cognitive, rather than chronological development,[18,47] especially in settings with nonsupportive families.[48] Understanding each person's role in a decision is key, which facilitates shared decision making for TGD youth.[49] However, some health care providers focus on provider responsibility and have concerns about acquiescing to youth wishes.[47]

TGD adults believe the health care provider role to be providing information about options and possible side effects.[40] Such knowledge enables decision making[16,25] and gives the TGD individual power to voice an opinion in the decision.[50]

Most individuals highly desire participation in decision-making processes, although a lack of treatment experience is associated with wanting less decision-making power.[51] Moreover, inconsistency in how options are presented or discussed[17] supports the need for a decision aid focused on risks, complications, and benefits of treatment.[25]

Decision-making processes. Across decisions, there were commonalities related to the complexity of decision making in the setting of gender care[16,41] due to

variation in preferences[20,41,51] and the need for individualized care.[29,46] There was also recognition of the interdependence of transition-related decisions, including hormones, contraception,[52] fertility preservation,[35–38] and surgery.[19] A need for exploration and careful consideration[16] becomes especially relevant as TGD youth regard their own body and treatment desires.[41]

The complexity of the decision-making process leads to differences in both decision-making preferences[51] and desires related to gender care itself.[41] Personalized advice[27,29] and a more transparent, individualized model of care,[46] may reduce the TGD community's distrust of the health care system,[46] which impacts decision making.

Sources of decision support. TGD individuals seek decision support outside the health care system,[50] especially from their social network[25] and families.[33,42] Information from peers is important in many individuals' gender care decisions[24,25] but may be inaccurate.[25] Blogs and online narratives help individuals understand the range of treatment possibilities.[6,53] At the same time, parents of TGD youth find it difficult to access accurate medical information and medical support.[54]

Several articles specifically addressed decision-support interventions. One reported that health care providers prioritized a decision aid over a provider assessment tool.[12] Two articles focused on a Dutch decision aid for gender-affirming surgery,[13,14] and found it had a positive effect but would have been more useful earlier in the decision process.[14] Finally, one study evaluated a class for adult patients, and their caregivers, used as a decision-support intervention for gender-affirming surgery.[15] It was associated with participants feeling better informed about options and possible surgical complications.[15]

Synthesis of decision-support tools

Decision-support tools received included patient education handouts, scientific articles, consent forms, websites, and resource lists. Tools focused on a wide variety of topics, including supporting TGD youth, legal resources, contraception, fertility preservation, puberty blockers and gender-affirming hormones, mental health, and surgery. Nearly a quarter (24.1%) of the items we received focused on puberty blockers and/or gender-affirming hormones. Forty-six items (31.7%) seemed directly aimed at youth, 7 (4.8%) at adult patients, 20 (13.8%) at parents, 12 (8.3%) at health professionals, and 9 (6.2%) at schools. All others had a nonspecific audience.

No resource we received qualified as a decision aid using the International Patient Decision Aid Standards.[11] Twenty (13.8%) out of the 145 unique resources received presented information about more than one option. Seven (35%) of those listed multiple options, without including risks and benefits of those options. The 13 which included information on risks and benefits included resources focused on gender-affirming hormones, tucking and binding, and contraception. One resource, focused on contraception, presented risks and benefits of different options side by side to facilitate comparison, a format which was not used by any other item we received. This resource met 5 out of 6 IPDASi criteria, but did not explicitly state the decision to be considered.

Discussion

Including published literature and resources currently used in clinical practice in this scoping review, enabled us to develop a holistic perspective on the current state of decision making and decision support in gender care. Overall, this review highlights the limited literature in this area and the complexity of gender care-related decision making, whether the patient is an adolescent or an adult. There are, however, decisions such as fertility preservation in which the individual's age contributes to the decision-making complexity.[18,47] Likewise, for TGD adolescents, the need, in most cases, to have parental consent for treatment complicates decision making.[55]

The greater emphasis on gender-affirming hormones among the decision tools, compared with the literature, likely reflects that the tools came from pediatric clinics but the literature largely focuses on adults. Additionally, the breadth of information covered by tools we received, highlights the vast number of decisions TGD youth and their families face. Finally, consistent with the lack of true decision aids we received, most studies addressed aspects of the decision-making process but did not consider interventions to support it.

Decision making in this setting has similarities to other medical decisions. As in other medical decisions, the right choice depends on the values and preferences of the individual, which may be impacted by the data available for a specific decision.[4] Many gender care decisions are made in the context of uncertainty related to both the scientific data and social outcomes of the

decision.[56] In other medical settings, shared decision making has been proposed as an approach to address such uncertainty, provide accurate information, and balance adolescent and parent input.[4,57]

Given individuals' desire to participate in the decision-making process[51] and the similarities between gender-related decisions and medical decisions in other settings, interventions to support gender-care decision making could be adapted from existing tools that facilitate shared decision making in pediatrics.[58,59]

While there are similarities to other medical decisions, gender-care decisions do have unique characteristics, particularly the interplay between social and medical decision making.[6] This interplay may be the reason that many studies included in this scoping review discuss the balance in power and roles played by health care providers, patients and, in some cases, parents,[6,43,46,49–51] along with transgender youths' decision-making capacity.[18,47] It may also lead to peer input influencing decision making.[24,25] Finally, the potential permanence of the decision is unusual in medical decision making for adolescents and complicated by an inability to predict future preferences,[29–32] and concern with potential future regret.[28] Although, at least for fertility preservation, there is little decisional regret.[38]

The diversity of decision foci included in this review outlines the many decisions TGD individuals face along the transition journey and the variations in decision-making processes. For example, for TGD adolescents, the length of time to make decisions about gender-affirming hormone therapy may be influenced by their parents' willingness to consent to treatment.[6,41] Perhaps because of the lack of data on the social aspect of many of these decisions, the decision process is influenced by others[6,24,34,50,53] and, particularly for TGD youth and their parents, involves seeking information from online resources.[6,53] Altogether, this suggests there may be multiple time points at which decision support could be offered and that current support within the medical system is inadequate.

Decision aids, which include personal narratives[60] from TGD individuals who have made these decisions or from parents of TGD youth, along with evidence-based information, may help ensure the quality of information, while addressing their desire for information from peers.

Although we used well-accepted methods[8,61] for this scoping review, the study does have limitations. First, key studies may have been overlooked. We minimized this risk through our broad search strategy, team-based review, and checking of the references of included studies. The nature of the studies identified, primarily qualitative and small surveys, potentially limits the generalizability of our findings, but the consistency among the studies suggests some overarching themes. Finally, we had limited responses to our request for decision-support tools. We suspect this reflects the current lack of tools, but there may be IPDASi-qualifying tools, of which we are unaware.

Conclusion

Only four[12–15] studies focused on decision-support interventions. This, combined with the challenges of decision making and the lack of existing decision-support tools, suggests the need for research focused on developing decision-support tools for TGD individuals, perhaps especially TGD youth and their parents.

Future work should also examine, within a research framework, the roles of insurance, health system, and legal system on decision making and decision support for TGD individuals. The results of this scoping review may serve as a starting point for engaging youth, parents, and health care providers in the development and testing of decision-support tools. Ultimately facilitating high-quality decision making related to gender care may lead to better communication between youth and parents, less uncertainty during the decision-making process, and decreased decisional regret. These, in turn, may improve the medical and psychosocial outcomes for TGD youth.

Authors' Contributions

A.L. made substantial contributions to the acquisition, analysis, and interpretation of data; drafted the article; gave final approval of the version to be published; and agrees to be accountable for all aspects of the work.

A.P. made substantial contributions to the acquisition, analysis, and interpretation of data; revised the article for critical intellectual content; gave final approval of the version to be published; and agrees to be accountable for all aspects of the work.

L.A.C. made substantial contributions to conception and design of the work, the acquisition, analysis, and interpretation of data; revised the article for critical intellectual content; gave final approval of the version to be published; and agrees to be accountable for all aspects of the work.

E.G.D. made substantial contributions to conception and design of the work, the acquisition of data, revised the article for critical intellectual content, gave final

approval of the version to be published, and agrees to be accountable for all aspects of the work.

E.P. made substantial contributions to the acquisition, analysis, and interpretation of data; revised the article for critical intellectual content, gave final approval of the version to be published, and agrees to be accountable for all aspects of the work.

L.M.V. made substantial contributions to conception and design of the work; the acquisition, analysis, and interpretation of data; revised the article for critical intellectual content; gave final approval of the version to be published; and agrees to be accountable for all aspects of the work.

E.A.L. made substantial contributions to conception and design of the work; the acquisition, analysis, and interpretation of data; drafted and revised the article for critical intellectual content; gave final approval of the version to be published; and agrees to be accountable for all aspects of the work.

Author Disclosure Statement

Amy Lambert, Ashli Pratt, Lee Ann Conard, Elaine Grigg Dean, Erica Page, and Lisa Vaughn have no disclosures. Ellen Lipstein had an institutional grant from Pfizer, Inc., for unrelated work.

Funding Information

This work was funded by a Cincinnati Children's Place Outcomes Research Award and a Cincinnati Children's Schmidlapp Women's Scholar Award.

Supplementary Material

Supplementary Appendix SA1
Supplementary Appendix SA2

References

1. Olson J, Forbes C, Belzer M. Management of the transgender adolescent. Arch Pediatr Adolesc Med. 2011;165:171–176.
2. Kimberly LL, Folkers KM, Friesen P, et al. Ethical issues in gender-affirming care for youth. Pediatrics. 2018;142:e20181537.
3. Olson-Kennedy J, Okonta V, Clark LF, Belzer M. Physiologic response to gender-affirming hormones among transgender youth. J Adolesc Health. 2018;62:397–401.
4. Politi MC, Lewis CL, Frosch DL. Supporting shared decisions when clinical evidence is low. Med Care Res Rev. 2013;70(1 Suppl):113S–128S.
5. Epstein RM, Gramling RE. What is shared in shared decision making? Complex decisions when the evidence is unclear. Med Care Res Rev. 2013; 70(1 Suppl):94S–112S.
6. Daley T, Grossoehme D, McGuire JK, et al. "I Couldn't See a Downside": decision-making about gender-affirming hormone therapy. J Adolesc Health. 2019;65:274–279.
7. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. Patient Educ Couns. 2006;60:301–312.
8. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169:467–473.
9. University of Minnesota Libraries. Search terms & Strategies. Library Resources for Transgender Topics Web site. Available at: https://libguides.umn.edu/transgender_topics/search_terms. Accessed November 18, 2019.
10. Human Rights Campaign. Interactive Map: clinical Care Programs for Gender-Expansive Children and Adolescents. Available at: www.hrc.org/resources/interactive-map-clinical-care-programs-for-gender-nonconforming-childr Accessed April 4, 2019.
11. Durand MA, Witt J, Joseph-Williams N, et al. Minimum standards for the certification of patient decision support interventions: feasibility and application. Patient Educ Couns. 2015;98:462–468.
12. Johnson EK, Chen D, Gordon EJ, et al. Fertility-related care for gender and sex diverse individuals: a provider needs-assessment survey. Transgend Health. 2016;1:197–201.
13. Özer M, Pigot GL, Bouman M-B, et al. Development of a decision aid for genital gender-affirming surgery in transmen. J Sex Med. 2018;15:1041–1048.
14. Mokken SE, Ozer M, van de Grift TC, et al. Evaluation of the decision aid for genital surgery in transmen. J Sex Med. 2020;17:2067–2076.
15. Poceta J, Cousins S, Wenzel C, et al. Effectiveness of a gender affirming surgery class for transgender and non-binary patients and their caregivers in an integrated healthcare setting. Int J Transgend. 2019;20:81–86.
16. Atnas C, Milton M, Archer S. Making the decision to change–the experiences of trans men. Couns Psychol Rev. 2015;30:33–42.
17. Hoffkling A, Obedin-Maliver J, Sevelius J. From erasure to opportunity: a qualitative study of the experiences of transgender men around pregnancy and recommendations for providers. BMC Pregnancy Childbirth. 2017;17(Suppl 2):332.
18. Bernacki JM, Weimer AK. Role of development on youth decision-making and recovery from gender-affirming surgery. Clin Pract Pediatr Psychol. 2019;7:312.
19. de Blok CJM, Staphorsius AS, Wiepjes CM, et al. Frequency, determinants, and satisfaction of breast augmentation in trans women receiving hormone treatment. J Sex Med. 2020;17:342–348.
20. Jacobsson J, Andreasson M, Kolby L, et al. Patients' priorities regarding female-to-male gender affirmation surgery of the genitalia-a pilot study of 47 Patients in Sweden. J Sex Med. 2017;14:857–864.
21. Jiang D, Witten J, Berli J, Dugi D, 3rd. Does depth matter? factors affecting choice of vulvoplasty over vaginoplasty as gender-affirming genital surgery for transgender women. J Sex Med. 2018;15:902–906.
22. Ettner R, Ettner F, White T. Choosing a surgeon: an exploratory study of factors influencing selection of a gender affirmation surgeon. Transgend Health. 2016;1:124–128.
23. Benson TA, Boskey ER, Ganor O. The effect of forearm tattoos on flap choice in transmasculine phalloplasty patients. MDM Policy Pract. 2020;5: 2381468320938740.
24. Rachlin K. Factors which influence individual's decisions when considering female-to-male genital reconstructive surgery. Int J Transgend. 1999;3:3.
25. Aguayo-Romero RA, Reisen CA, Zea MC, et al. Gender affirmation and body modification among transgender persons in Bogotá, Colombia. Int J Transgend. 2015;16:103–115.
26. Jokic-Begic N, Lauri Korajlija A, Jurin T. Psychosocial adjustment to sex reassignment surgery: a qualitative examination and personal experiences of six transsexual persons in croatia. Sci World J. 2014;2014: 960745.
27. van de Grift TC, Pigot GLS, Boudhan S, et al. A Longitudinal study of motivations before and psychosexual outcomes after genital gender-confirming surgery in transmen. J Sex Med. 2017;14:1621–1628.
28. Garcia MM, Christopher NA, De Luca F, et al. Overall satisfaction, sexual function, and the durability of neophallus dimensions following staged female to male genital gender confirming surgery: the Institute of Urology, London U.K. experience. Transl Androl Urol. 2014;3:156–162.
29. Kyweluk MA, Sajwani A, Chen D. Freezing for the future: transgender youth respond to medical fertility preservation. Int J Transgend. 2018;19: 401–416.
30. Nahata L, Tishelman AC, Caltabellotta NM, Quinn GP. Low fertility preservation utilization among transgender youth. J Adolesc Health. 2017;61: 40–44.
31. Strang JF, Jarin J, Call D, et al. Transgender youth fertility attitudes questionnaire: measure development in nonautistic and autistic transgender youth and their parents. J Adolesc Health. 2018;62:128–135.

32. Riggs DW, Bartholomaeus C. Fertility preservation decision making amongst Australian transgender and non-binary adults. Reprod Health. 2018;15:181.
33. Birenbaum-Carmeli D, Inhorn MC, Patrizio P. Transgender men's fertility preservation: experiences, social support, and the quest for genetic parenthood. Cult Health Sex. 2021;23:945–960.
34. Chen D, Kyweluk MA, Sajwani A, et al. Factors affecting fertility decision-making among transgender adolescents and young adults. LGBT Health. 2019;6:107–115.
35. Kerman HM, Pham A, Crouch JM, et al. Gender diverse youth on fertility and future family: a qualitative analysis. J Adolesc Health. 2021;68:1112–1120.
36. Persky RW, Gruschow SM, Sinaii N, et al. Attitudes toward fertility preservation among transgender youth and their parents. J Adolesc Health. 2020;67:583–589.
37. Stuyver I, Somers S, Provoost V, et al. Ten years of fertility treatment experience and reproductive options in transgender men. Int J Transgend Health. 2021;22:294–303.
38. Vyas N, Douglas CR, Mann C, et al. Access, barriers, and decisional regret in pursuit of fertility preservation among transgender and gender-diverse individuals. Fertil Steril. 2021;115:1029–1034.
39. Chen D, Matson M, Macapagal K, et al. Attitudes toward fertility and reproductive health among transgender and gender-nonconforming adolescents. J Adolesc Health. 2018;63:62–68.
40. Bartholomaeus C, Riggs DW. Transgender and non-binary Australians' experiences with healthcare professionals in relation to fertility preservation. Cult Health Sex. 2020;22:129–145.
41. Pullen Sansfaçon A, Temple-Newhook J, Suerich-Gulick F, et al. The experiences of gender diverse and trans children and youth considering and initiating medical interventions in Canadian gender-affirming speciality clinics. Int J Transgend. 2019;20:371–387.
42. Clark BA, Marshall SK, Saewyc EM. Hormone therapy decision-making processes: transgender youth and parents. J Adolesc. 2020;79:136–147.
43. Clark BA, Virani A. This Wasn't a Split-Second Decision": an empirical ethical analysis of transgender youth capacity, rights, and authority to consent to hormone therapy. J Bioethical Inquiry. 2021;18:151–164.
44. Fein LA, Salgado CJ, Alvarez CV, Estes CM. Transitioning transgender: investigating the important aspects of the transition: a brief report. Int J Sex Health. 2017;29:80–88.
45. Beek TF, Kreukels BP, Cohen-Kettenis PT, Steensma TD. Partial treatment requests and underlying motives of applicants for gender affirming interventions. J Sex Med. 2015;12:2201–2205.
46. Eyssel J, Koehler A, Dekker A, et al. Needs and concerns of transgender individuals regarding interdisciplinary transgender healthcare: a non-clinical online survey. PLoS One. 2017;12:e0183014.
47. Vrouenraets LJ, Fredriks AM, Hannema SE, et al. Early medical treatment of children and adolescents with gender dysphoria: an empirical ethical study. J Adolesc Health. 2015;57:367–373.
48. Clark BA, Virani A, Saewyc EM. "The edge of harm and help": ethical considerations in the care of transgender youth with complex family situations. Ethics Behav. 2020;30:161–180.
49. Clark BA, Virani A, Marshall SK, Saewyc EM. Conditions for shared decision making in the care of transgender youth in Canada. Health Promot Int. 2021;36:570–580.
50. Linander I, Alm E, Hammarstrom A, Harryson L. Negotiating the (bio)medical gaze - Experiences of trans-specific healthcare in Sweden. Soc Sci Med. 2017;174:9–16.
51. Mayer TK, Koehler A, Eyssel J, Nieder TO. How gender identity and treatment progress impact decision-making, psychotherapy and aftercare desires of trans persons. J Clin Med. 2019;8:749.
52. Agenor M, Cottrill AA, Kay E, et al. Contraceptive beliefs, decision making and care experiences among transmasculine young adults: a qualitative analysis. Perspect Sex Reprod Health. 2020;52:7–14.
53. Evans YN, Gridley SJ, Crouch J, et al. Understanding online resource use by transgender youth and caregivers: a qualitative study. Transgend Health. 2017;2:129–139.
54. Riley EA, Sitharthan G, Clemson L, Diamond M. The needs of gender-variant children and their parents: a parent survey. Int J Sex Health. 2011; 23:181–195.
55. Rafferty J, Committee on Psychosocial Aspects of Child and Family Health, et al. Ensuring comprehensive care and support for transgender and gender-diverse children and adolescents. Pediatrics. 2018;142:e20182162.
56. Vance SR, Jr., Ehrensaft D, Rosenthal SM. Psychological and medical care of gender nonconforming youth. Pediatrics. 2014;134:1184–1192.
57. Gabe J, Olumide G, Bury M. 'It takes three to tango': a framework for understanding patient partnership in paediatric clinics. Soc Sci Med. 2004;59:1071–1079.
58. Wyatt KD, List B, Brinkman WB, et al. Shared decision making in pediatrics: a systematic review and meta-analysis. Acad Pediatr. 2015;15:573–583.
59. Feenstra B, Boland L, Lawson ML, et al. Interventions to support children's engagement in health-related decisions: a systematic review. BMC Pediatr. 2014;14:109.
60. Shaffer VA, Zikmund-Fisher BJ. All stories are not alike: a purpose-, content-, and valence-based taxonomy of patient narratives in decision AIDS. Med Decis Making. 2013;33:4–13.
61. Peters MD, Godfrey CM, Khalil H, et al. Guidance for conducting systematic scoping reviews. Int J Evid Based Healthcare. 2015;13:141–146.

Cite this article as: Lambert A, Pratt A, Conard LAE, Grigg Dean E, Page E, Vaughn LM, Lipstein EA (2023) Supporting gender-related medical decision making for transgender and gender-diverse individuals: a scoping review, *Transgender Health* 8:2, 113–123, DOI: 10.1089/trgh.2021.0030.

Abbreviation Used

TGD = transgender and gender-diverse